DOCUMENT RESUME

ED 382 328 PS 023 089

AUTHOR Durch, Jane S., Ed.
TITLE Protecting and Improving Quality of Care for Children under Health Care Reform: Workshop Highlights.
INSTITUTION National Academy of Sciences - National Research Council, Washington, DC. Committee on Maternal and Child Health under Health Care Reform.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.; March of Dimes Birth Defects Foundation, Washington, D.C.; Public Health Service (DHHS), Rockville, MD. Office of Disease Prevention and Health Promotion.
PUB DATE 94
CONTRACT ASU-000002-01
NOTE 22p.
AVAILABLE FROM Division of Health Promotion and Disease Prevention, Institute of Medicine, 2101 Constitution Avenue, N.W., Washington, DC 20418 (Quantities are limited).
PUB TYPE Viewpoints (Opinion/Position Papers, Essays, etc.) (120)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Accountability; *Child Health; Government Role; *Health Needs; *Health Services; *Medical Care Evaluation; *Medical Services; Mothers; Research Methodology; Workshops
IDENTIFIERS *Health Care Reform; Maternal Health

ABSTRACT

This report discusses the quality of health care for children in light of national health care reform proposals put forth in 1994, and is based on presentations and discussions at an invitational workshop on maternal and child health. The report examines issues related to: (1) the differences between health care provision for children and adults; (2) the dependent status of children; (3) children's patterns of illness and injury; (4) monitoring the quality of children's care needs, including medical and non-medical services; (5) the identification of additional indicators to assess children's health; (6) the establishment of accountability for the quality of the care that children receive; and (7) the need for further research to develop better techniques and tools to support assessments of the quality of children's health care. Two appendices provide a list of related publications from the Institute of Medicine and the National Research Council and a list of workshop participants. (MDM)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)
X This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 382 328

Protecting and Improving Quality of Care for Children Under Health Care Reform

Workshop Highlights

Committee on
Maternal and Child Health Under Health Care Reform

PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY
W.M. Burns
TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)

NATIONAL RESEARCH COUNCIL

INSTITUTE OF MEDICINE

PS 023089

BEST COPY AVAILABLE

Protecting and Improving Quality of Care for Children Under Health Care Reform

Workshop Highlights

Committee on
Maternal and Child Health Under Health Care Reform

Jane S. Durch, Editor

Board on Children and Families
Commission on Behavioral and Social Sciences and Education
National Research Council / Institute of Medicine

and

Board on Health Promotion and Disease Prevention
Institute of Medicine

NATIONAL RESEARCH COUNCIL
INSTITUTE OF MEDICINE
Washington, D.C. 1994

NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

The National Academy of Sciences is a private, nonprofit, self-perpetuating society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Upon the authority of the charter granted to it by the Congress in 1863, the Academy has a mandate that requires it to advise the federal government on scientific and technical matters. Dr. Bruce Alberts is president of the National Academy of Sciences.

The Institute of Medicine was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of the appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under the Academy's 1863 congressional charter responsibility to be an adviser to the federal government and its own initiative in identifying issues of medical care, research, and education. Dr. Kenneth I. Shine is president of the Institute of Medicine.

The National Research Council was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the Academy's purposes of furthering knowledge and advising the federal government. Functioning in accordance with general policies determined by the Academy, the Council has become the principal operating agency of both the National Academy of Sciences and the National Academy of Engineering in providing services to the government, the public, and the scientific and engineering communities. The Council is administered jointly by both Academies and the Institute of Medicine.

Funding for this project was provided by the U.S. Department of Health and Human Services through the Office of the Assistant Secretary for Health (cooperative agreement number ASU-000002-01) and the Maternal and Child Health Bureau, by the March of Dimes Birth Defects Foundation, and by the National Foundation for Public Health Policy. The views presented in this report are those of the Committee on Maternal and Child Health Under Health Care Reform and the participants in the workshop and are not necessarily those of the funding organizations.

Additional copies of this report are available in limited quantities from:

Division of Health Promotion and Disease Prevention
Institute of Medicine
2101 Constitution Avenue, N.W.
Washington, DC 20418

Copyright 1994 by the National Academy of Sciences. All rights reserved.

Printed in the United States of America

COMMITTEE ON MATERNAL AND CHILD HEALTH UNDER HEALTH CARE REFORM

MARY JANE ENGLAND *(Chair)*, President, Washington Business Group on Health, Washington, D.C.

ANA O. DUMOIS, Executive Director, Community Family Planning Council, New York City

HENRY W. FOSTER, JR.,* Professor of Obstetrics and Gynecology, Meharry Medical College, and Scholar-in-Residence, Association of Academic Health Centers, Washington, D.C.

KATHERINE E. GRIMES, Director of Child Psychiatry Training, Harvard Community Health Plan, Brookline, Massachusetts, and Clinical Instructor, Department of Psychiatry, Harvard Medical School

BERNARD GUYER, Professor and Chairman, Department of Maternal and Child Health, The Johns Hopkins School of Hygiene and Public Health

KAY KNIGHT HANLEY, Private practice of pediatrics, Clearwater, Florida

ELIZABETH A. McGLYNN, Senior Researcher, The RAND Corporation, Santa Monica, California

JAMES M. PERRIN, Director of Ambulatory Care Programs and General Pediatrics, Children's Service, Massachusetts General Hospital, Boston, and Associate Professor of Pediatrics, Harvard Medical School

Staff

Cynthia Abel, Program Officer
Drusilla Barnes, Senior Project Assistant
Sarah S. Brown, Senior Program Officer
Jane S. Durch, Program Officer
Deborah A. Phillips, Director, Board on Children and Families
Michael A. Stoto, Director, Division of Health Promotion and Disease Prevention

*Institute of Medicine member.

Preface

This report is based on presentations and discussions at an invitational workshop on maternal and child health under health care reform held on July 7–8, 1994, in Washington, D.C. The workshop was organized by the Board of Health Promotion and Disease Prevention of the Institute of Medicine (IOM) and the Board on Children and Families, which operates under the joint auspices of the Institute of Medicine and the Commission on Behavioral and Social Sciences and Education of the National Research Council (NRC). A steering committee (see committee roster, p. iii) was appointed to oversee the workshop and preparation of resulting reports, including this one. These reports do not present formal recommendations. Funding for this project was provided by the U.S. Department of Health and Human Services through the Office of the Assistant Secretary for Health and the Maternal and Child Health Bureau, by the March of Dimes Birth Defects Foundation, and by the National Foundation for Public Health Policy.

Because of the rapidly changing legislative picture at the time of the workshop, a systematic comparison of the provisions of the various reform proposals that had been submitted over the past several months and others that were then emerging from House and Senate committees was not attempted. Underlying most of the presentations and discussion, however, was a general assumption that changes were already occurring in the health care system that would lead to further growth of managed care and integrated health systems regardless of federal legislative action.

Key issues addressed during the first day of the workshop included benefits and systems of care for mothers and children. The second day focused primarily on quality improvement and performance monitoring for children's health care services. Brief presentations by various speakers were the starting point for more extensive discussion throughout the workshop. Participants included health care and public health professionals among whose activities are the delivery of services, research, and policy development; representatives of federal agencies; and congressional staff. A list of speakers appears in Appendix B.

The attention at the workshop and in this report to the special features of monitoring the quality of children's health care is consistent with a broader concern at the IOM with issues of quality of care in the face of changes in the health care system. A special initiative, designated "America's Health in Transition: Protecting and Improving the Quality of Health and Health Care," will lead to an examination of many such issues over the next three years. The first product of this initiative, a White Paper issued in July 1994, underscores the importance of attention to quality-of-care issues as health care reform moves forward. Appendix A lists several related IOM and NRC publications.

Several people were particularly helpful to the staff in formulating the agenda and identifying possible speakers: Donald Berwick, Institute for Health Care Improvement; Amy Fine, Association of Maternal and Child Health Programs; Neal Halfon, UCLA School of Public Health; Kay Johnson, March of Dimes Birth Defects Foundation; Woodie Kessel, Maternal and Child Health Bureau; Jonathan Kotch, National Foundation for Public Health Policy; Kristen Langlykke and Pamela Mangu, National Center for Education in Maternal and Child Health; Sara Rosenbaum and Elizabeth Wehr, the George Washington University Center for Health Policy Research; and Lisa Simpson and Robert Valdez, Office of the Assistant Secretary for Health. The comments received from formally designated reviewers helped refine and strengthen the report.

Numerous staff members in addition to those listed with the workshop steering committee contributed to the success of the workshop and the preparation of this report: Brenda Buchbinder, Claudia Carl, Nancy Crowell, Molla Donaldson, Judith Doody, Michael Edington, Eugenia Grohman, Carrie Ingalls, Amanda Klekowski, Philomina Mammen, Alison Smith, and Mary Thomas. For both the workshop and this report, Kathleen Lohr, director of IOM's Division of Health Care Services, provided particularly valuable advice on quality-of-care issues.

Contents

SUMMARY 1

INTRODUCTION 3

ASSESSING THE QUALITY OF CARE 3

ASSESSING CHILDREN'S HEALTH AND HEALTH CARE 4
Critical Differences Between Children and Adults, 4
More than Medical Care for Children's Health, 5
Conceptual and Methodological Considerations, 6

ASSESSING QUALITY AT SEVERAL LEVELS 7

ACCOUNTABILITY FOR CHILDREN'S CARE 7

DEVELOPING AND ENHANCING RESOURCES FOR ASSESSING CHILDREN'S CARE 9

CONCLUSIONS 9

APPENDIXES
A Related Publications from the Institute of Medicine and the National Research Council 10

B Workshop Participants 11

Protecting and Improving the Quality of Care for Children Under Health Care Reform: Workshop Highlights

SUMMARY

Changes in the financing and delivery of health care across the United States make it particularly important to ensure that the quality of care is both protected and improved. The Institute of Medicine (IOM) has defined quality of care as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."* A workshop organized by the National Research Council and IOM identified several critical factors that affect our ability to protect and improve the quality of health care for children in particular.

Valuable, but still limited, techniques and tools are available to evaluate certain aspects of care for adults. Some resources are available to guide and monitor children's care, but assessing the quality of children's health care poses special challenges. The workshop highlighted the importance of certain critical differences between children and adults, the contribution of many services beyond medical care to a child's healthy development, and conceptual and methodological issues.

Critical differences between children and adults include the complex and continuing ***developmental changes*** that occur between birth and adulthood. Care for children emphasizes protecting and promoting healthy physical and psychosocial development whereas much adult care responds to illness. To assess children's care, ways must be developed to identify the separate effects of health care and developmental changes.

Children also are ***dependent*** on adults and community institutions (e.g., schools) to protect and promote their health and well-being. Assessments of their health status cannot, therefore, rely on the criterion used for adults of "independent functioning." Assessments also often rely on adult perceptions of a child's condition, which may differ from the child's perceptions or from those of other adults.

---

*Institute of Medicine. 1990. *Medicare: A Strategy for Quality Assurance*. K.N. Lohr, ed. Vol. I. Washington, D.C.: National Academy Press, p. 21.

Children's ***patterns of illness and injury*** differ from those of adults. Overall, children are healthier than adults, and therefore, assessments of children's care must focus more on preventive care than assessments for adults. The small proportion of children who have chronic illnesses have a more varied array of illnesses than do adults.

Monitoring the quality of children's care needs to include the contributions of medical care plus other services that help promote optimal physical and psychosocial development. Medical care can mitigate some of the impact of socioeconomic and environmental health threats and can help children gain access to additional services that can improve their health and well-being. Successful integration of health care with educational and social services appears valuable but techniques are needed to assess the quality of those integrated services.

Additional indicators are needed to assess the quality of children's health care. The few that are commonly used touch on only limited aspects of the care given to children. ***Health status measures*** suitable for guiding policy and assessing the outcomes of care also require further development. In addition, important ***methodological problems need to be resolved***, including measuring the impact of prevention, developing statistically reliable measures to assess the care of small numbers of children with specific chronic illnesses or other special health care needs, and developing techniques for risk adjustment that are appropriate for all aspects of pediatric care.

Assessments of health and health care can be made from three perspectives: the individual patient and provider, health plan performance, and systems of services for entire communities and states. Further development of ***measures and tools for all three forms of assessment*** is still needed.

Establishing accountability for the quality of the care that children receive is a special concern. Simply measuring performance does not ensure that problems will be corrected. Well-established criteria to define "medically necessary" or clinically appropriate care for children are not available, and administrative and legal remedies may not offer adequate protection for children in low-income families or other vulnerable populations. The array of public and private services that contribute to children's health and development need coordination and oversight. Workshop participants felt that federal and state health care reforms need to include ***mechanisms that will lead to action by health plans, public health agencies, or other entities to respond to identified problems.***

Discussions throughout the workshop emphasized the need for ***further research*** to develop better techniques and tools to support assessments of the quality of children's health care. The workshop discussions also drew attention to the need to ***develop better data, data collection, and data systems*** to support efforts to monitor and improve children's care.

INTRODUCTION

As actions at the state and local levels and in the public and private sectors change the financing and delivery of health care across the United States, there is concern that the quality of care must be protected and enhanced.[1] Anticipated federal health care reform legislation offers the possibility of important changes in health care financing and increased access to care; it also offers a greater opportunity than in the past to ensure that the essential function of monitoring quality of care is explicitly addressed. Successful monitoring of care for adults will not be simple, but monitoring the quality of health care for children[2] poses special challenges. Measures are needed to assess not only treatment of illness but also preventive care and promotion of optimal physical and psychosocial development over the roughly 20-year period from birth to adulthood.

In response to concern that important aspects of children's health and health care require greater attention as federal health care reform proposals take final shape and as other aspects of federal health programs are developed, the National Academy of Sciences' National Research Council (NRC) and Institute of Medicine (IOM) held an invitational workshop on July 7-8, 1994. At the request of the Office of the Assistant Secretary for Health in the U.S. Department of Health and Human Services, the second day of the workshop focused on protecting and improving the quality of care for children. This brief report, prepared under the guidance of the workshop steering committee, summarizes the major points raised in presentations and discussion.

ASSESSING THE QUALITY OF CARE

As defined by the IOM, "quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[3] This definition reflects several important points: the process of care (health services) can be linked to the outcome of care (health or health status), quality assessments should consider care for individuals and that received by defined groups (e.g., members of a health plan or an entire community), and care should be guided by accepted professional standards and by preferences expressed by patients (or their families). The definition applies to health services to meet physical or psychosocial needs and to services offered by many kinds of health care providers.

Assessments of care can identify problems in the form of poor health outcomes or inappropriate health services (use of unnecessary or ineffective care, lack of needed care, or shortcomings in technical and interpersonal aspects of care). Identifying poor health outcomes is

---

[1]The Institute of Medicine has addressed concerns about quality in all aspects of health care in a white paper issued by the IOM Council in July 1994, *America's Health in Transition: Protecting and Improving Quality* (Washington, D.C.: National Academy Press).

[2]As used in this report, the term "children" encompasses infants through adolescents.

[3]Institute of Medicine. 1990. *Medicare: A Strategy for Quality Assurance*. K.N. Lohr, ed. Vol. I. Washington, D.C.: National Academy Press, p. 21.

critical for evaluating the effectiveness of care and shaping policy. To improve outcomes, however, policymakers and health care providers must have information about the processes of care that produced those outcomes.

Work over the past 30 years has led to the development of valuable but still limited techniques and tools for assessing and improving the quality of health care. Presentations at the workshop reviewed some of the measures that have been developed for children and pointed out that less progress has been made than for adults, in part because of factors such as limited funding for research on children's health and special ethical concerns that arise for research involving children.

Increasing interest in monitoring quality and in reporting measures of health care performance (e.g., with health plan report cards) is helping to draw greater attention to the need to develop better quality assessment techniques and tools for both adults and children. Workshop participants emphasized, however, that efforts to monitor and improve the quality of care should move ahead using the available tools, even though perfect measures are not yet available.

ASSESSING CHILDREN'S HEALTH AND HEALTH CARE

Workshop discussions highlighted several factors that contribute to the complexity of assessing children's health and health care: certain critical differences between children and adults; the impact on a child's healthy development of services beyond the scope of traditional medical care; and conceptual and methodological issues in developing quality measures for children.

Critical Differences Between Children and Adults

Three differences between children and adults were cited as particularly significant for assessing health status and health care:

1. *Developmental changes*. Between birth and adulthood, children experience a complex and continuing process of physical and psychosocial development, with certain vulnerable periods in which appropriate care is essential for optimal developmental progress. Even subtle shifts from what would have been a child's "normal" developmental track may have a life-long impact.

Because some of the criteria for healthy functioning and for appropriate care change as children move through this developmental process, techniques for assessing their health status and quality of care need to reflect those changes. Among adults, adverse effects of illness and the compensatory effect of health care can often be assessed against a relatively stable level of functioning immediately before the illness. Among children, however, the effects of an illness and of health care can be much harder to judge against the background of developmental changes that occur within a wide range of normal functioning. For some children, a long-term assessment process may be needed to determine the full impact of either health care or illness.

2. *Dependency*. Children are inherently dependent on their parents and other adults as well as community institutions (including schools) to protect and promote their health and well-being.

Therefore, the element of "independent functioning," which is a critical factor in judging adult health status, does not apply to children. The degree of dependency decreases over time, but in large measure children must rely on adults, as individuals or through society's various institutional structures, to provide care that promotes normal development, to recognize disorders and obtain treatment, and to define pre- and posttreatment functioning. Some workshop participants pointed out, however, that adults' perceptions of a child's condition may not match the child's perceptions; even among adults, the judgements of parents and health professionals may differ from each other.

3. *Patterns of illness and injury*. Children have a characteristic epidemiology of health and illness. Most children are fundamentally healthy and require care that emphasizes preventive services, such as immunizations and monitoring of physical and psychosocial growth and development. By comparison, adult care is based much more on response to illness. Patterns of serious illness in children, especially chronic illness, also differ from those in adults. Relatively small numbers of children experience a diverse array of conditions in contrast to the larger number of adults who, in general, experience a more limited and more predictable range of disorders. The diversity of children's conditions means that few health professionals have the expertise or resources to provide the full range of care for all such conditions and that families may need help gaining access to specialized support services. Furthermore, these children need care not only for the illness itself but also to minimize possible adverse effects of the illness on overall development.

More than Medical Care for Children's Health

Workshop participants emphasized that optimal health and development for many children requires not only medical care but also other health and social services both to prevent problems and to ameliorate the effects of conditions that do have an adverse impact on children. The discussions pointed to the need to consider the contribution of those services in addition to medical care in at least some assessments of the quality of children's care.

Many important health threats lie in socioeconomic and environmental factors, such as poverty and community violence, that are not the traditional targets of clinical preventive services. If these risk factors are not addressed, however, the health care system must often provide acute or chronic care for conditions such as injuries, exposure to toxic substances (e.g., lead), or emotional disturbances. For some children, a range of social services may be needed to provide comprehensive care for a chronic illness, to ensure adequate nutrition, to promote a safe home environment, or to respond successfully to certain "behavior" problems that may not typically be viewed as health related.

Even though medical care cannot "cure" social and environmental problems, it can mitigate some of the adverse health effects and facilitate access to the variety of other services that can promote better health and development for children. Some of the services may be available from health plans or other health care providers, while others may be provided by public health agencies, often with federal support such as Maternal and Child Health Block Grant funds. Education and school-based services, which often are more removed from the realm of medical care, also make important contributions to a child's health and developmental progress.

The problem of injury, a leading cause of death among children, clearly illustrates the need to combine personal health services with broader public health and community efforts. The health care system provides acute, and sometimes rehabilitative and chronic, care for injured children, but its contribution to prevention is primarily counseling for parents and children about avoidable risks. Effective prevention also depends on activities such as public education, enacting and enforcing safety laws (e.g., for bicycle helmets, pool fencing, or sale of alcohol to minors), and special programs such as school-based violence prevention training for children.

Many workshop participants felt that successful integration of health care, education, and social services is particularly valuable in meeting children's unique health and developmental needs. The diversity of these services, however, makes it less clear how to monitor the quality of the care that they provide. Health plans may have an interest in assessing how well such services are meeting the needs of member children, but public health agencies have a broader perspective that can enable them, in collaboration with providers in the private sector, to make overall assessments of these services for all children in a state or community.

Conceptual and Methodological Considerations

Rates of immunization, low birth weight, and hospitalization for asthma are among the handful of indicators used to monitor children's health care. These measures touch on only a few aspects of the care given to children, but there is little consensus about the merits of other measures. An informal survey of pediatricians, which was described at the workshop, has produced suggestions that the process of routine preventive care be monitored on the basis of procedures such as vision screening, assessment of language development, or measurement of weight, height, and head circumference.

Although monitoring the quality of care focuses on process, the outcomes of care—usually assessed with health status measures—must also be considered. Workshop participants emphasized that, for children, the concepts of health and health outcomes are not easily defined but must be broader than the presence or absence of disease. The elements of developmental change and dependency, which were discussed above, contribute to the complexity of assessing children's health status and functional outcomes. Strong support was voiced at the workshop for the development of generic measures, but some participants saw merit in disease-specific measures as well. Some tools for health status assessment are less appropriate for clinical evaluation and are intended for community-based assessments and policy guidance. Many national assessments rely on the National Health Interview Survey, but the sample size is too small to provide data for state-level or condition-specific assessments.

Developing reliable and valid process measures poses several methodological problems. An assessment of preventive care, for example, must contend with two issues: how to measure events that do *not* occur (or occur very rarely) because that care was given, and how to evaluate effects of care over a very long time span. Some measures may be useful but not appropriate for children of all ages: for example, immunization rates for 2-year-olds reflect care being given to infants and toddlers but do not provide information about care that adolescents are receiving. Children with chronic illnesses or other special health care needs receive substantial amounts of care, but the small

numbers of such children make it hard to develop measures with adequate statistical power to detect meaningful differences over time or among health plans.

One of the anticipated uses of quality measures is to facilitate comparisons of the care provided by health plans. For such comparisons to be fair, adjustments must be made for significant differences in the underlying health of the populations served by plans or for other factors outside of the control of health plans (e.g., members' socioeconomic characteristics or differences in benefit packages selected by employers) that might lead to entirely appropriate differences in care or outcomes of care. Available adult-based adjustment techniques may not be satisfactory for children and should not be used unless they can be validated for a pediatric population. Work done in pediatric populations has largely focused on mortality risks among critically ill or injured children. Because such methods apply to only a small number of children, more broadly based approaches are needed as well.

ASSESSING QUALITY AT SEVERAL LEVELS

Assessments of the quality of health and health care for children (or adults) can be made from at least three perspectives: the individual patient and provider, health plan performance, and systems of services for entire communities and states. Workshop participants emphasized the importance of the broad perspective of population-based assessments, which make it possible to examine patterns of care and identify gaps in services.

Health plans, which can examine the care provided to the population represented by their members, can use assessments to obtain information to support their internal quality improvement programs. Those assessments can also help purchasers and consumers of health services select among competing plans. Individual health plans are not, however, in a position to assess whether a community's entire population has health insurance coverage, and they may not accept responsibility for assessing how well plan services mesh with those that children may receive (or need) from other sources.

Communities and states seem to be the levels at which overall assessments should be made. Public health agencies can work with health plans and other private providers to make assessments, but they will need adequate financial and technical resources to do so. The tools (appropriate measures and survey instruments or other data collection systems) needed for all but the most basic assessments require further development. Reliable national-level data also need to be collected to monitor the overall health of children and families.

ACCOUNTABILITY FOR CHILDREN'S CARE

Assessing quality of care does not by itself ensure that problems that are identified will be corrected. Workshop participants expressed concern that without adequate means to monitor children's care, a particularly vulnerable population could be put at even greater risk in the midst of a changing health care system that tends to focus on adult needs and may face stronger incentives to control costs than to improve care.

To the extent that quality assessments are possible, they will promote correction of some problems. For example, given the appropriate information, many health care providers will take what steps they can to make improvements. Publication of performance measures for health plans may encourage those with lower ratings to make improvements so that they can compete successfully with other plans. If children's unique needs are considered, accreditation standards established by private, voluntary groups can also promote improvements in quality of care provided by hospitals, health plans, or other providers that want to achieve accredited status. Since it is not possible to monitor all aspects of care, accreditation standards may also promote good quality of care through attention to the structural aspects of health care (e.g., numbers and qualifications of providers, availability of beds and proper equipment).

Many workshop participants felt, however, that these mechanisms would not be sufficient to protect and improve the quality of children's care. They saw a need for federal and state health care reforms to establish other means to ensure that health plans or other responsible parties take action to correct any deficiencies in the care they are providing to children.

Discussions pointed to two particularly important motivations for public sector involvement in establishing accountability for the quality of children's care. The first factor is a need for a recognized standard of care for children that can be used to establish appropriate criteria for "medically necessary" care. The currently limited amount of science-based evidence for formulating pediatric practice guidelines may lead health plans to rely on adult-oriented standards for medical necessity. Those standards may result in care that is not in the best interests of children by, for example, offering access to adult rather than pediatric specialists or limiting coverage for home-based care, which could avoid the adverse developmental effects of prolonged hospitalization. There was also concern that children in low-income families and other vulnerable groups (including adolescents who may be alienated from their families) could have difficulty taking advantage of administrative and legal mechanisms to challenge health plan judgements on the medical necessity of specific kinds of care.

The second motivation for public sector involvement in monitoring quality of care is the need for coordination and oversight of the full array of public and private services that contribute to children's health and development. Unless a public health department or other entity is given explicit responsibility for monitoring and improving this package of services, the separate components may not mesh effectively and children may not benefit as they should from those services. Some at the workshop felt that authority for all quality oversight should rest with state public health agencies. They noted that the IOM has identified as core public health functions assessing health status and health needs and assuring that high quality services are available to meet those needs.[4]

---

[4]These functions were first identified in *The Future of Public Health* (Institute of Medicine, 1988, Washington, D.C.: National Academy Press). They were recently reaffirmed in the IOM Council's July 1994 white paper, *America's Health in Transition: Protecting and Improving Quality* (Washington, D.C.: National Academy Press).

DEVELOPING AND ENHANCING RESOURCES FOR ASSESSING CHILDREN'S CARE

Throughout the workshop, presentations and discussions pointed to the need for federal assistance to support research to develop appropriate techniques and tools for assessing the quality of children's health care. Some of these research needs are noted here. Research is needed to develop measures of health status and functional outcomes that are suited to monitoring the impact of health care on children as well as measures that can meet other clinical and policy needs. Studies must continue to examine the effectiveness of various kinds of preventive, curative, and rehabilitative care across the pediatric age range. More and better clinical practice guidelines for pediatric care are needed. Work is also needed to develop ways to promote the integration of the broad range of services that contribute to the health and well-being of children and to assess and improve the quality of this system and the services it is providing.

A second theme that emerged from the workshop was the need to develop better data, data collection, and data systems to support efforts to monitor and improve care. Some states (e.g., Massachusetts and Washington) are already taking steps to ensure that they have statewide data systems and data reporting requirements that will allow them to monitor health care. Other states and communities may need technical assistance to establish assessment and improvement programs. Better use of existing public and private data sources and data systems may make it possible to develop needed information in a particularly cost-effective manner. Relevant federal and state data, for example, could be made more readily available to communities. National guidelines will be needed to promote comparability of quality data across the country.

Several specific suggestions were made for improving the usefulness of national surveys and data systems (e.g., vital statistics) for monitoring children's health status and the impact of health care reform: evaluating and improving measures of child health, developing the capability to assess both short- and long-term effects of illness and health care on children's health status, instituting longitudinal data collection (e.g., through panel surveys), expanding national surveys so that they can produce state-level estimates, and developing the capability specifically to monitor vulnerable child populations.

CONCLUSIONS

As changes are made in the health care system to control costs and improve access to services, changes should also ensure that the quality of care is protected and improved. To ensure that children receive appropriate care, the available, but still limited, tools for assessing their health status and health care need to be used as effectively as possible. Development of a more comprehensive set of quality indicators will require rigorous studies that examine the effectiveness of various elements of children's care. Programs to monitor quality of care will need to establish accountability for correcting problems that may be found and mechanisms to ensure that improvements are made.

Appendix A

Recent Publications from the Institute of Medicine and the National Research Council Related to Quality of Care Issues Discussed at the Workshop on Maternal and Child Health Under Health Care Reform

Institute of Medicine

The Future of Public Health. Washington, D.C.: National Academy Press. 1988.

Clinical Practice Guidelines: Directions for a New Program. M.J. Field and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1990.

Medicare: A Strategy for Quality Assurance. K.N. Lohr, ed. Vols. I and II. Washington, D.C.: National Academy Press. 1990.

Guidelines for Clinical Practice: From Development to Use. M.J. Field and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1992.

Access to Health Care in America. M. Millman, ed. Washington, D.C.: National Academy Press. 1993.

Assessing Health Care Reform. M.J. Field, K.N. Lohr, and K.D. Yordy, eds. Washington, D.C.: National Academy Press. 1993.

Emergency Medical Services for Children. J.S. Durch and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1993.

America's Health in Transition: Protecting and Improving Quality. A Statement of the IOM Council. Washington, D.C.: National Academy Press. 1994.

Health Data in the Information Age: Use, Disclosure, and Privacy. M.S. Donaldson and K.N. Lohr, eds. Washington, D.C.: National Academy Press. 1994.

National Research Council and Institute of Medicine

Including Children and Pregnant Women in Health Care Reform: Summary of Two Workshops. S.S. Brown, ed. Washington, D.C.: National Academy Press. 1992.

Toward a National Health Care Survey: A Data System for the 21st Century. G.S. Wunderlich, ed. Washington, D.C.: National Academy Press. 1992.

Other Publications

Advances in Health Status Assessment: Proceedings of a Conference. 1989. K.N. Lohr, ed. *Medical Care* 27(March Suppl.):S1-S294.

Advances in Health Status Assessment: Proceedings of a Conference. 1992. K.N. Lohr, ed. *Medical Care* 30(May Suppl.):MS1-MS293.

Appendix B

Workshop on Maternal and Child Health Under Health Care Reform
July 7–8, 1994

Speakers

HOWARD BAUCHNER, Associate Professor of Pediatrics, Boston University School of Medicine, and Scholar-in-Residence, Center for the Future of Children, The David and Lucille Packard Foundation, Los Altos, California

ROBERT F. COLE, Director, Mental Health Services Program for Youth, Washington Business Group on Health, Washington, D.C.

STAN DORN, Managing Attorney, Washington Office, National Health Law Program

ILENE FENNOY, Acting Senior Vice President, Medical and Professional Affairs, Health and Hospitals Corporation, New York City

STEVEN FOLDES, Research Manager, Center for Health Services Research and Evaluation, Blue Cross Blue Shield of Minnesota—Blue Plus, St. Paul

NEAL HALFON, Associate Professor of Pediatrics and Public Health, School of Public Health, University of California at Los Angeles

KAREN HEIN, Robert Wood Johnson Fellow, Committee on Finance, United States Senate, Washington, D.C., and Associate Professor of Pediatrics, Albert Einstein College of Medicine, New York City

CATHERINE HESS, Executive Director, Association of Maternal and Child Health Programs, Washington, D.C.

CHARLES E. IRWIN, Jr., Professor of Pediatrics, and Director, Division of Adolescent Medicine, University of California at San Francisco

KAY A. JOHNSON, Director, Policy and Government Affairs, March of Dimes Birth Defects Foundation, Washington, D.C.

LUELLA KLEIN, Charles H. Candler Professor, Department of Gynecology & Obstetrics, Emory University School of Medicine, Atlanta, Georgia

MARGARET A. McMANUS, McManus Health Policy, Inc., Washington, D.C.

C. ARDEN MILLER, Professor of Maternal and Child Health, School of Public Health, University of North Carolina at Chapel Hill

EUGENE C. NELSON, Professor of Community and Family Medicine, Dartmouth Medical School, and Director of Quality Education, Measurement, and Research, Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire

PAUL NEWACHECK, Professor of Health Policy, Institute for Health Policy Studies, University of California at San Francisco

LUCY OSBORN, Associate Vice President for Clinical Programs, University of Utah Health Sciences Center, Salt Lake City

ANN E.K. PAGE, Director of Program Development, National Committee for Quality Assurance, Washington, D.C.

IAN RAWSON, Senior Vice President, Allegheny General Hospital, Pittsburgh, Pennsylvania

KENNETH I. SHINE, President, Institute of Medicine, Washington, D.C.

LISA SIMPSON, Senior Policy Analyst, Office of the Assistant Secretary for Health, Department of Health and Human Services, Washington, D.C.

BARBARA STARFIELD, Professor and Head, Division of Health Policy, The Johns Hopkins University School of Hygiene and Public Health, Baltimore, Maryland

RUTH E.K. STEIN, Professor of Pediatrics, Albert Einstein College of Medicine, and Department of Pediatrics, Bronx Municipal Hospital Center, Bronx, New York

ROBERT VALDEZ, Deputy Assistant Secretary for Health, PHS (Designate), and Director, Interagency Health Policy, HCFA, Department of Health and Human Services, Washington, D.C.

DEBORAH VON ZINKERNAGEL, Health Policy Advisor, Committee on Labor and Human Resources, United States Senate, Washington, D.C.

LOREN N. VORLICKY, Senior Vice President and Southern Region Medical Director, Hitchcock Clinic, Bedford, New Hampshire

DEBORAH K. WALKER, Assistant Commissioner, Massachusetts Department of Health, Boston

ELIZABETH WEHR, Research Associate, Center for Health Policy Research, The George Washington University, Washington, D.C.

KATY WELKIE, Nursing Director, Pediatric Intensive Care Unit, Primary Children's Medical Center, Salt Lake City, Utah

Invited Guests

MOLLY A. ANTHONY, Vice President for Research and Policy Analysis, National Association of Children's Hospitals and Related Institutions, Alexandria, Virginia

NAOMI J. BANKS, Senior Research Analyst, Center for Quality of Care, Harvard School of Public Health, Boston, Massachusetts

KATHY BRYANT, Director of Government Relations, American College of Obstetricians and Gynecologists, Washington, D.C.

JOSEPH S. CASSELLS, Interim Executive Officer, Institute of Medicine, Washington, D.C.

CAROLYN M. CLANCY, Director, Division of Primary Care, Agency for Health Care Policy and Research, Rockville, Maryland

TANIA DAVIS, Research Assistant, Research and Evaluation Department, Robert Wood Johnson Foundation, Princeton, New Jersey

MARGE DEGNON, Executive Secretary, Ambulatory Pediatric Association, McLean, Virginia

CHRISTOPHER DeGRAW, Senior Research Staff Scientist, Center for Health Policy Research, The George Washington University, Washington, D.C.

MOLLA S. DONALDSON, Senior Program Officer, Institute of Medicine, Washington, D.C.

ALISON EVANS, Research Analyst, National Academy of Social Insurance, Washington, D.C.

AMY FINE, Senior Policy Analyst, Association of Maternal and Child Health Programs, Washington, D.C.

JORDAN W. FINKELSTEIN, Medical Officer, Center for Research on Mothers and Children, National Institute for Child Health and Human Development, Bethesda, Maryland

VIVIAN GABOR, Senior Associate, Office of Government Affairs, March of Dimes Birth Defects Foundation, Washington, D.C.

RICHARD C. GILBERT, Director, State and Local Affairs, American Public Health Association, Washington, D.C.

SUSANNA GINSBURG, Vice President, Lewin-VHI, Fairfax, Virginia

MORRIS GREEN, Perry W. Lesh Professor of Pediatrics, Riley Hospital for Children, Indianapolis, Indiana

JOAN GREENE, President, National Association of Pediatric Nurse Associates and Practitioners, Washington, D.C.

DEAN GROSS, Policy Fellow, Office of Program Development, Agency for Health Care Policy and Research, Rockville, Maryland

KATHY HALLISSEY, Administration on Children and Families, Department of Health and Human Services, Washington, D.C.

JAMES W. HANSON, Senior Advisor, National Vaccine Program Office, U.S. Public Health Service, Washington, D.C.

MARY HEBERT, Associate, Prevention Leadership Forum, Washington Business Group on Health, Washington, D.C.

DAVID HEPPEL, Director, Division of Maternal, Infant, Child and Adolescent Health, Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland

ROBERT HUGHES, Director of Program Research, Research and Evaluation Department, Robert Wood Johnson Foundation, Princeton, New Jersey

HENRY T. IREYS, Assistant Professor, Department of Maternal and Child Health, The Johns Hopkins University School of Hygiene and Public Health, Baltimore, Maryland

WOODIE KESSEL, Director, Division of Systems Education and Science, Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland

JOHN KIELY, Chief, Infant and Child Health Studies Branch, National Center for Health Statistics, Hyattsville, Maryland

JANE KOPPELMAN, Senior Research Associate, National Health Policy Forum, Washington, D.C.

TRISHA KURTZ, Research Assistant, National Committee for Quality Assurance, Washington, D.C.

KALA LADENHEIM, Senior Research Associate, Intergovernmental Health Policy Project, The George Washington University, Washington, D.C.

KATHLEEN N. LOHR, Director, Division of Health Care Services, Institute of Medicine, Washington, D.C.

PAMELA B. MANGU, Director, Division of Programs, National Center for Education in Maternal and Child Health, Arlington, Virginia

PAMELA MITTELSTADT, Director, Medical Affairs Department, Group Health Association of America, Washington, D.C.

AMY NEVEL, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Washington, D.C.

ELENA NIGHTINGALE, Senior Program Officer and Special Advisor to the President, Carnegie Corporation of New York, Washington, D.C.

AUDREY H. NORA, Director, Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland

JACKIE NOYES, Associate Executive Director, American Academy of Pediatrics, Washington, D.C.

DONNA O'HARE, Clinical Professor of Pediatrics, New York School of Medicine, and Project Director, MIC/FP, MHRA, New York City

JULIA R. PLOTNICK, Chief Nurse Officer, USPHS, and Associate Director, Division of Children with Special Health Care Needs, Maternal and Child Health Bureau, Rockville, Maryland

SUSAN ROGERS, Research Coordinator, CMEES, Research Triangle Institute, Rockville, Maryland

PATRICIA A. ROWELL, Senior Policy Fellow, Department of Practice, Economics, and Policy, American Nurses Association, Washington, D.C.

MICHAEL SANDERS, AMSA Health Policy Fellow, Division of Primary Care, Agency for Health Care Policy and Research, Rockville, Maryland

RAFAEL SEMANSKY, National Committee for Quality Assurance, Washington, D.C.

MARGARET SKELLEY, Director of Public Health Programs, Association of State and Territorial Health Officials, Washington, D.C.

MICHELE SOLLOWAY, Senior Research Scientist, Center for Health Policy Research, The George Washington University, Washington, D.C.

COLLEEN SONOSKY, Research Associate, Center for Health Policy Research, The George Washington University, Washington, D.C.

STEPHANIE SPERNAK, Senior Research Scientist, Center for Health Policy Research, The George Washington University, Washington, D.C.

PETERS D. WILLSON, Vice President for Government Relations, National Association of Children's Hospitals and Related Institutions, Alexandria, Virginia

ROBIN ZINK, Washington Representative, National Association of Pediatric Nurse Associates and Practitioners